DOCUMENT RESUME

ED 343 295 EC 300 974

TITLE	Sexuality and Developmental Disabilities: An Investigation of Sexual Incidents at Bernard Fineson Developmental Center.
INSTITUTION	New York State Commission on Quality of Care for the Mentally Disabled, Albany.
PUB DATE	91
NOTE	38p.
PUB TYPE	Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Adults; *Compliance (Legal); Due Process; *Institutionalized Persons; Institutional Role; Investigations; Legal Responsibility; Personal Autonomy; Quality Control; Residential Institutions; *Severe Mental Retardation; *Sexual Abuse; *Sexuality; Supervision
IDENTIFIERS	*Bernard Fineson Developmental Center NY; *Consent

ABSTRACT

This report is the result of an investigation by the New York State Commission on Quality of Care for the Mentally Disabled of the Bernard Fineson Developmental Center's policies and practices concerning sexual incidents among residents. It also raises broader issues about the meaning of consent when sexual activity involves persons with severe or profound mental retardation. The report concludes that the Center's lack of supervision has failed to protect residents and allowed numerous serious incidents to occur including those in which residents were forced into unwanted sexual activity by other residents and those in which one partner was too mentally impaired to be able to give consent. Deficiencies were found over all four mandated incident management functions--the reporting, investigation and review of incidents as well as the implementation of corrective actions. Individual sections of the report address: general background; state law and regulations of the Office of Mental Retardation and Developmental Disabilities; reporting and classification deficiencies (with three case reports); deficiencies in the investigation of incidents; Incident Review Committee proceedings; the questionable implementation of corrective action; recommendations; broader issues; and corrective actions. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED343295

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Sexuality and Developmental Disabilities: An Investigation of Sexual Incidents at Bernard Fineson Developmental Center

New York State Commission on Quality of Care
for the Mentally Disabled

"PERMISSION TO REPRODUCE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

G. W. Mashire

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

©1991 Commission on Quality of Care for the Mentally Disabled

BEST COPY AVAILABLE

Sexuality and Developmental Disabilities: An Investigation of Sexual Incidents at Bernard Fineson Developmental Center

Clarence J. Sundram
CHAIRMAN

William P. Benjamin
Elizabeth W. Stack
COMMISSIONERS

November 1991

NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED

Preface

The fabric of this report is primarily monochromatic. It deals with one primary issue—the failure of the Bernard Fineson Developmental Center to protect its residents from harm. Specifically, this report describes the lack of supervision of residents which allowed numerous serious incidents to occur, and the failure of the incident reporting and review process to enhance the safety of residents by reducing the likelihood that the same or similar incidents will recur. Many incidents described herein were sexual: some involved incidents in which residents were forced into unwanted sexual activity by other residents; other incidents involved sexual activity in which one partner, according to the facility's own determination, was too mentally impaired to be able to give consent to the activity.

The case examples cited in this report portray a system which failed to comply with both the letter of the law (MHL §29.29) and the spirit of the Office of Mental Retardation and Developmental Disabilities' (OMRDD) incident reporting regulations (14 NYCRR Part 624) and in so doing left vulnerable residents unprotected, and kept from administrators, clinicians and direct care staff information essential to the responsible fulfillment of their duties.

The deficiencies were apparent over all four mandated incident management functions—the reporting, investigation and review of incidents and the implementation of corrective actions.

Specifically:

- Some serious incidents of forcible sexual assaults, attempted rape and sodomy were not reported either internally or externally to oversight and law enforcement agencies.
- Of those incidents which were reported, several serious ones were misclassified which lessened the scrutiny they received.
- Investigations of incidents were often cursory and closed prematurely, leaving unanswered questions and/or with conclusions not supported in fact.
- The Chair of the Incident Review Committee who reviewed all investigations, and the Committee as a body failed to question the adequacy of the investigations.
- There was no system in place to ensure the implementation of effective corrective actions.

There is, however, one thread in the fabric of this report which is a different color and it focuses the reader on questions regarding sexual activity among persons with severe or profound mental retardation.

Because the bulk of this report describes the mishandling of several tragic and shocking incidents, the reader might be tempted to view the consent issue only as a flashy distraction and dismiss it without consideration. Alternately, if the reader follows only this thread and loses sight of its place in the "whole cloth" of this investigation, (s)he may fail to recognize, as some facility staff did, the uncontestable obligation of the facility to keep residents safe.

Having fixed the consent issue in its proper context *vis a vis* this report, the Commission recognizes the need for a discussion of the issue of capacity to consent to sexual activity among severely mentally retarded persons. (See pp. 22-26)

It is evident to the Commission that, although OMRDD regulations are clear in defining as "sexual abuse" all sexual activity between clients and others, or among clients unless all involved clients are "consenting adults" (14 NYCRR Part 624.2(b)(2)), many staff appear not to understand the concept of

capacity to consent. Some facility administrators apparently have not resolved their own ambivalent feelings about physically non-coercive sexual activity involving persons who do not have the capacity to consent. Their ambivalence sends confusing messages to other staff about how they should respond to such sexual incidents among residents.

As a result of this confusion, lack of understanding or simply disagreement with the plain duty to report and investigate incidents which constitute "sexual abuse" as defined in the regulations, these duties were often not carried out by staff and administrators.

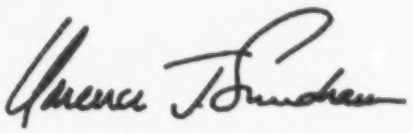
This report illustrates how the protections intended to be provided to residents of mental retardation facilities by state law and regulations are eviscerated when these duties are disregarded.

The Commission notes that in response to this investigation, the Commissioner of OMRDD has promulgated draft guidelines to assist facilities in clearly understanding their obligations to promote the ability of people in their custody to live as normal lives as possible, while at the same time protecting vulnerable people from harm. These draft guidelines forthrightly address the difficult and complex issues of determining when people with developmental disabilities lack the capacity to consent, thus triggering the protective role of the provider. They further assist providers in carrying out their obligations to provide care, habilitation, training and support services to enhance the autonomy and decision-making abilities of people with developmental disabilities.

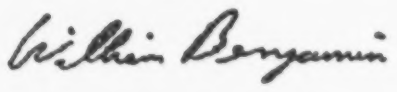
The Commission recognizes that each of the issues addressed by OMRDD's draft guidelines may be disputed by some providers and advocates. It is precisely because of such anticipated controversy that, for years, there has been little official guidance to staff and programs on how to deal with seemingly conflicting values, sometimes with the types of consequences described in this report.

We commend the Commissioner of OMRDD for her willingness to bring this issue out into the open and to try to find the right balance between respecting rights to privacy and self-determination and clearly protecting vulnerable people from harm and exploitation.

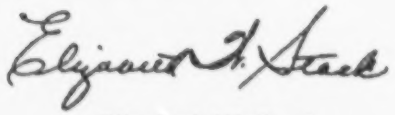
The findings and conclusions of this report represent the unanimous opinion of the members of the Commission. A draft of this report was shared with the Office of Mental Retardation and Developmental Disabilities. The actions taken by OMRDD and Bernard Fineson Developmental Center are summarized at the end of the report.



Clarence J. Sundram
CHAIRMAN



William P. Benjamin
COMMISSIONER



Elizabeth W. Stack
COMMISSIONER

Table of Contents

Background 1

State Law and OMRDD Regulations 3

Methods 4

Reporting and Classification Deficiencies 7
- Case #1 7
- Case #2 9
- Case #3 9

Deficiencies in the Investigation of Incidents 10

Incident Review Committee Proceedings 13

Corrective Action Implementation Questionable 17

Where Next?— Additional Recommendations 19

The Broader Issues 22

Summary of Recommendations 27

Corrective Actions 29

Staff Acknowledgements

Project Director

Betty Jane Chura

Investigators

Gladys DeJesus-Tuccillo
Stephen Hirschhorn
Jerry Montrym
Corinne Romanotto
Pamela Williams

Production

Christine Blackman
Marcus Gigliotti

Background

In response to an allegation by the mother of a mentally retarded adult resident of Bernard Fineson Developmental Center that her son Mark[1] was being sexually victimized by one or more other male residents, the Commission conducted an investigation into this allegation and reviewed, in general, the Corona Unit's[2] handling of the sexual activity of residents on the sixth and seventh floors. These residents are generally the most active and skilled persons living at the site, although the functioning level of residents varies considerably on each floor. This is particularly true of the sixth floor where some residents are diagnosed as mildly retarded and others as profoundly retarded, and where some residents are quite fluent and others are nonverbal.

Staff had been instructed to view sexual activity as a private matter and not to record it in ward logs. CQC staff also learned that 13 of the 24 sexually active residents on the sixth and seventh floor were receiving sexual education or counseling, that condoms were not available because no one was teaching residents how to use them, and that the clinical staff had not determined which residents were capable of consenting to sexual activity and which were not.

At the time of this initial review, January, 1989, the facility was aware that some residents were sexually active with each other and, in one instance known to CQC, with partners in the community. The facility maintained that these sexual experiences were appropriate, for the most part, because those persons involved had developed a relationship or at least did not object to the activity.

Commission staff attempted to ascertain who, if anyone, could have forced himself on Mark. This prompted a more generalized inquiry aimed at determining what staff knew of the residents' activities and what measures were taken by the facility to protect residents from sexual advances. When asked to indicate which residents were sexually active, staff gave widely varying answers to this question. This was explained, at least in part, by a senior facility administrator's remarks that staff had been instructed to view sexual activity as a private matter and not to record it in ward logs. CQC staff also learned that 13 of the 24 sexually active residents on the sixth and seventh floor were receiving sexual education or counseling, that condoms were not available because no one was teaching residents how to use them, and that the clinical staff had not determined which residents were capable of consenting to sexual activity and which were not.

In response to the Commission's concerns that the lack of safeguards to protect vulnerable residents who could not consent to sexual activity and the risks of sex with multiple partners were not being assessed and

[1] All residents' names used in this report are pseudonyms.

[2] Bernard Fineson Developmental Center is located at three sites in Queens, New York. The three sites are the Hillside Unit, the Howard Park Unit and the Corona Unit.

In response to the Commission's concerns that the lack of safeguards to protect vulnerable residents who could not consent to sexual activity and the risks of sex with multiple partners were not being assessed and addressed, the facility reported in July 1989 that it had initiated corrective actions.

addressed, the facility reported in July 1989 that it had initiated corrective actions. These included:

- ❑ training additional clinicians in the Sexual Awareness Program;
- ❑ increasing the number of residents in sexuality counselling;
- ❑ engaging a trainer from Planned Parenthood to teach condom use; and
- ❑ determining for each of the residents his/her capacity to consent to sexual activity.

A follow-up CQC review in August, 1990 revealed that many of the corrective actions had been implemented. Significantly, all capacity determinations had been made, condom training had been conducted, and sex education and training had been made available to more residents. However, problems surfaced during this and a subsequent review on January 15, 1991 when CQC staff asked for copies of incident reports of incidents of a sexual nature to evaluate how they were being handled. When they were told that there was only one such incident, CQC staff probed further and learned from staff of two other serious incidents discussed later in the report -- one involving Debra Miller and Michael Evans and the second involving six unsupervised residents. The facility's handling of these incidents led Commission staff to undertake on January 30 a review of the incident reporting and review process.

State Law and OMRDD Regulations

A well-functioning incident review system brings to light problems and investigates their causes so that program managers can take effective corrective measures to minimize the risk of recurrence of the same or similar events.

Section 29.29 of Mental Hygiene Law requires the Commissioners of the Offices of Mental Health and Mental Retardation and Developmental Disabilities to ". . .establish policies and uniform procedures for their respective offices for the compilation and analysis of incident reports." The OMRDD incident reporting regulations articulate more fully the responsibility of state-operated and certified programs to implement a system of incident management which ensures the reporting, investigating, reviewing and correcting and monitoring of untoward events. The review of incidents is to be conducted by a standing committee convened regularly for that purpose. The purposes of the incident review system are to "enhance the quality of care provided clients and to ensure that they are free from mental and physical abuse." A well-functioning incident review system brings to light problems and investigates their causes so that program managers can take effective corrective measures to minimize the risk of recurrence of the same or similar events.

The OMRDD regulations define incidents according to their nature and seriousness and establish special reporting procedures for the most serious. For example, all serious reportable incidents and all allegations of client abuse must be reported to the OMRDD immediately by phone or other appropriate method, and a completed Incident Reporting Form must follow within 24 hours. Leaves without consent, serious injuries requiring a hospital or infirmary stay of 24 hours or more, any possible criminal act on the part of a client and any allegation of client abuse are examples of serious reportable incidents. Client abuse includes all sexual activity except between consenting adults. Any allegation of client abuse must also be reported to the Commission on a completed Incident Reporting Form within 72 hours of discovery.

Methods

To ascertain whether incidents were being reported on incident report forms and forwarded from the units to the facility administration, the first and necessary step in the process, Commission staff read the records of approximately 60 percent of the residents of the sixth floor of the Corona Unit, reviewed the ward logs and tracked the untoward events identified in these documents through the incident reporting and review process for the previous six months. These investigative actions, taken over a two day period, revealed that the incident review functions were not implemented as required by OMRDD Regulations, Part 624.

Overall, the incident review system evidenced a failure to appreciate the seriousness of several incidents, leading to non-reporting or misclassification which resulted in circumvention of a rigorous review; substantial inadequacies in the investigation of some incidents and the failure of the Incident Review Committee (IRC) to identify these; and the absence of a mechanism to ensure that corrective actions are implemented and are effective. While these deficiencies were evidenced over a variety of types of incidents, they were particularly noticeable in incidents involving sexual activity among the residents.

Overall, the incident review system evidenced a failure to appreciate the seriousness of several incidents, leading to non-reporting or misclassification which resulted in circumvention of a rigorous review; substantial inadequacies in the investigation of some incidents and the failure of the Incident Review Committee (IRC) to identify these; and the absence of a mechanism to ensure that corrective actions are implemented and are effective.

* * * *

The Commission's visits over the preceding 24 months focused, in large part, on the protection of residents not able to consent to sexual activity and encouraged the facility to evaluate the capacity to consent to sexual activity for each resident for whom this was questionable. The treatment teams completed an assessment sheet usually at the time of the individual's annual program review which indicated whether the resident was sexually active, whether this activity was appropriate and whether the person had the capacity to consent.

It is important to note that the OMRDD regulations governing incident reporting (14 NYCRR, Part 624) define sexual abuse, in part, as "any sexual activity between clients and others or among clients... *unless the involved client(s) is a consenting adult.* Sexual abuse includes any touching or fondling of a client directly or through clothing for the arousing or gratifying of sexual desires." The regulations further require that all such allegations are to be reported, investigated, reviewed by the Incident Review Committee and acted upon in an appropriate manner to safeguard the well-being of clients and to bring the matter to closure.

Further, all such allegations must be immediately reported to OMRDD and followed up in writing on Form OMR/147A, Allegation of Client Abuse. They must also be reported to the Commission pursuant to the Mental Hygiene Law (§45.19).

The definition of sexual abuse cited above derives from Penal Law, Article 130 which defines various sex crimes including rape, sexual misconduct, sodomy and sexual abuse. The law specifically notes that *lack of consent* is an element in each of these offenses. It states that a person is deemed *incapable of consent* when he is "less than 17 years old or mentally defective or mentally incapacitated or physically helpless." In defining a person who has a mental defect, the law notes that such a defect or disease renders the person "incapable of appraising the nature of his conduct." It explains this phrase further as requiring "an ability to understand the physiological nature of the sexual act and its consequences and an ability to understand and appreciate how such conduct will be regarded in the framework of the societal environment and taboos to which a person will be exposed. . .." (*People v. Easley*, 42 NY2d 50, 56 (1977))

Thus, by reference to the capacity assessments, one could determine when sexual activity between residents was the choice of two consenting adults and when it constituted "sexual abuse" as defined by OMRDD regulations because one or both of the partners was not capable of consent. According to the then Director of Quality Assurance, individuals were considered sexually active if they *sought out* a sexual partner or if they engaged in sexually self-stimulatory behavior in public settings. Thus, persons who were *only* unwilling or non-objecting partners in sexual incidents were not noted as sexually active.

According to the Director of Quality Assurance, clinicians' reluctance to determine that residents lacked the capacity to consent stemmed from a concern that such a determination would lessen the avenues of sexual expression open to residents so assessed.

In some cases when clinicians were apparently not comfortable in making an absolute determination of capacity, they equivocated, noting that a resident is "not always" capable of giving consent or that the person is capable "with counseling." According to the Director of Quality Assurance, clinicians' reluctance to determine that residents lacked the capacity to consent stemmed from a concern that such a determination would lessen the avenues of sexual expression open to residents so assessed. In response to such concerns, the facility modified the original assessment form several times. The revised form includes more descriptive/narrative information related to the person's decision-making skills, self-awareness, social awareness and self-direction. Among the information included in this assessment is a description of how the person expresses his/her feelings, to what extent the person can discriminate between friendship and intimacy, and whether the person is capable of benefitting from sexuality counseling or education. The assessment concludes with two questions: Does this person demonstrate the ability to consent to sexual activity; and, does this person demonstrate the ability to protect himself/herself against the unwanted sexual advances of others?

This latter question is an attempt to broaden the determinants of consent to allow the treatment team the flexibility to find "consent" in

"non-objection." While well-intentioned, as this report will later detail, the equivocations in the facility's treatment of the issue of consent contributed significantly to a failure of staff to recognize the victimization of vulnerable residents.

The equivocations in the facility's treatment of the issue of consent contributed significantly to a failure of staff to recognize the victimization of vulnerable residents.

As noted, prompted by these preliminary findings of the January 15 review, which suggested the possibility of systemic and serious incident reporting and investigation failures, four CQC staff visited the facility on January 30 and 31, 1991. The results of this review revealed that some serious or unusual incidents, often involving sexual activity, were not reported as incidents, were inadequately investigated and reviewed, sometimes circumventing the IRC altogether, and corrective actions to ensure that vulnerable residents were protected were consequently not forthcoming. Furthermore, for those incidents which were reviewed by the IRC, there was no mechanism in place to ensure the implementation of corrective actions. The following cases illustrate these points.

Reporting and Classification Deficiencies

THE COMMISSION'S REVIEW REVEALED THAT SEVERAL SERIOUS INCIDENTS WERE NOT REPORTED, EITHER INTERNALLY OR TO THE APPROPRIATE OVERSIGHT AND LAW ENFORCEMENT AGENCIES, AND OTHERS WERE MISCLASSIFIED, SHORT CIRCUITING THE REVIEW PROCESS.

Case #1

On October 19, 1990, Debra Miller and Michael Evans (both in their mid-twenties) left the dining room together after lunch unnoticed by staff. They were found shortly by a safety officer in a stairwell after they inadvertently tripped the intrusion alarm. Debra was naked while Michael was fully clothed. Michael, moderately mentally retarded, verbal, relatively street-wise, and known to be sexually active with several other clients, initially told the safety officer that nothing had happened. During this exchange, he was observed stuffing Debra's panties behind a pipe behind the stairwell door. Program staff examined this area and found many pairs of underwear there (some labeled, some not) belonging to several female residents.

Upon learning of the incident three months after it had occurred, CQC asked the facility to report the incident to the police since, by Bernard Fineson's own determination, Ms. Miller did not have the capacity to consent to sexual activity.

Both Ms. Miller and Mr. Evans were examined by a physician. No semen was found on either of them and Debra evidenced no signs of trauma. At the time of this exam, Michael informed the physician that he had had sexual relations with Debra on that day and often in the past. In response to this admission, Debra, who is profoundly mentally retarded and non-verbal, was seen by a gynecologist. He ran tests for syphilis and gonorrhea, took a pap smear, performed an exam for the presence of sperm, and placed Debra on birth control pills. The test results available three days later showed no sperm, ruled out gonorrhea and syphilis, but chlamydia was suspected. Erythromycin was ordered for Ms. Miller, but no further tests or cultures were ordered to verify or rule out chlamydia.

Upon learning of the incident three months after it had occurred, CQC asked the facility to report the incident to the police since, by Bernard Fineson's own determination, Ms. Miller did not have the capacity to consent to sexual activity. Mental Hygiene Law §7.21(b) charges the facility director with the responsibility to notify the district attorney or other appropriate law enforcement officials as soon as possible, and in any event within three working days, when it appears that a crime may

have been committed. The facility agreed and the police came but would not accept the report.

Commission staff also called the Deputy Commissioner of Quality Assurance for the Office of Mental Retardation and Developmental Disabilities (OMRDD) when they learned that an incident report had been completed and an investigation was begun, but the report was "pulled" before it reached the Incident Review Committee and was not reported to the OMRDD or the Commission. Reportedly the Treatment Team Leader and the Director of Quality Assurance, without reference to the consent capacity of the partners, had jointly decided that since sexual intercourse most likely had not been completed, no sexual abuse had occurred and, hence, no incident. They also reportedly were concerned about violating the residents' privacy.

Reportedly the Treatment Team Leader and the Director of Quality Assurance, without reference to the consent capacity of the partners, had jointly decided that since sexual intercourse most likely had not been completed, no sexual abuse had occurred and, hence, no incident. They also reportedly were concerned about violating the residents' privacy.

At the request of the Commission and of the OMRDD Deputy Commissioner for Quality Assurance, in mid-January 1991, the Facility Director re-opened and completed the investigation herself. This review concluded:

- There was lack of supervision of individuals in the dining room on October 19, 1990, as no one was aware that the two clients in question were missing.
- An OMR 147 incident report should have been completed and the incident should have been reviewed by the IRC. (This was subsequently done on January 17, 1991).
- A special team meeting should have occurred immediately following the initial investigation to discuss Ms. Miller's behavior and the team should have decided whether this incident warranted her being placed on birth control pills. The physician acted independently of the team in ordering birth control pills, and Ms. Miller's correspondent was not notified about the medications, as required, until January 17, 1991.

The Facility Director also concluded that there was no "coverup" of the incident by the actions of the Treatment Team Leader and the Director of Quality Assurance in short circuiting the reporting and investigative process.

The Facility Director noted that confusion over the meaning of capacity to consent to sexual activity contributed to the decision to not treat the situation as an incident. Although she had been determined not capable of giving informed consent to sexual activity because of the severity of her retardation, Ms. Miller was reportedly considered by some staff to be able to protect herself against unwanted sexual advances. It is this mind-set discussed earlier which explains to some degree the failure of the facility to view the incident as sexual abuse or an attempted sexual assault.

The Director's investigation also failed, as did the initial one, to pursue the questions raised by the pile of underwear in the stairwell and Mr. Evans' assertion that he had had sex with Debra in the past. No special precautions were taken to ensure that she and other residents

lacking capacity were protected in situations other than in or en route to the dining room.

Case #2

Similarly, in March 1990 Martha, who is profoundly retarded, non-verbal and, according to the facility, lacks the capacity to consent to sexual activity, was involved in a rape or attempted rape. Martha was heard screaming in her bedroom; staff pushed aside her barricaded bedroom door to find her naked with a naked male resident. Two other male residents looked on. The residents were dispersed and Martha was helped to dress. She was given no medical follow-up, no incident report was filed, no investigation ensued and the police were not called. The unit log for the day noted "no incidents or problems. . . ."

She was given no medical follow-up, no incident report was filed, no investigation ensued and the police were not called. The unit log for the day noted "no incidents or problems. . . ."

When CQC investigators read the nursing notes several months after the event and brought the incident to the attention of the Director for Quality Assurance, the facility responded by conducting training on incident reporting policies and procedures. The male residents involved were also counselled.

Case #3

A similar failure to see the seriousness of a sexual incident and to appreciate the perspective of the victims is revealed in the facility's handling of a September 16, 1990 incident. On that date, six residents (4 males, 2 females) were found to have had their pubic hair shaved at the insistence of Michael Evans (who was involved in the sexual incident with Debra). Two of the four men had been involved in the sexual assault of Martha described above. The facility investigated the incident and learned that both of the women involved were coerced. Martha (the victim of the attempted rape) reportedly was held down by one of the male residents while the second resident shaved her pubic area. Christine reported that she was afraid not to cooperate because the day before Michael Evans had hit her in the eye in the presence of two staff. A BFDC psychologist who routinely interviews residents involved in incidents and who interviewed Christine came to the conclusion that she "consented to the shaving" even while acknowledging that the "consent" was forthcoming from fear of further physical attack. The investigator took no action to ascertain whether the blow to Christine's eye had been reported on an incident report and investigated.

When questioned as to why this incident was not considered an assault or sexual abuse and why it was merely classified as a reportable incident, which does not require notification to the OMRDD or to CQC, the Director of Quality Assurance stated that she did not view it as serious, in part, because the actions were more for experimentation than sexual purposes.

When questioned as to why this incident was not considered an assault or sexual abuse and why it was merely classified as a reportable incident, which does not require notification to the OMRDD or to CQC, the Director of Quality Assurance stated that she did not view it as serious, in part, because the actions were more for experimentation than sexual purposes. The Incident Review Committee accepted recommendations for corrective actions discussed later in this report which called for increased supervision of residents.

Deficiencies in the Investigation of Incidents

THE INVESTIGATIONS CONDUCTED ON INCIDENTS WHICH WERE REPORTED WERE OFTEN CURSORY, FAILED TO PURSUE ALL THE QUESTIONS PRESENTED OR TO INTERVIEW AND TAKE STATEMENTS FROM ALL THE AVAILABLE WITNESSES, AND REACHED CONCLUSIONS WITHOUT EVIDENT BASES.

The three cases cited above illustrate a lack of appreciation of the facility's fundamental obligation to protect vulnerable residents through the accurate reporting and classification of incidents. Further CQC inquiry also revealed the facility's frequent failure to adequately investigate incidents.

As noted above, the facility took no action either during the first or second investigation to determine whether the female residents whose underwear was discovered behind the pipe in the stairwell were victimized by Mr. Evans and whether sexual encounters were occurring in other settings. While the corrective action taken by the facility in locking that stairwell was appropriate, there is no indication that the Treatment Team pursued a clinical response to these behaviors. This is particularly significant since three of the women whose underwear was found there were determined by the facility to not be capable of giving informed consent to sexual activity. (It remains unclear exactly how many women's underwear were found. Administrative staff reported to CQC that the underwear was inventoried at the time of the incident. Staff who were directly involved deny this. In any case, at the time of the CQC investigation, a list could not be found. CQC interviews with staff revealed the names of three women.)

The failure to interview all relevant parties and pursue questions raised during the investigation, shortcuts in taking statements and drawing conclusions in the absence of any evident basis for them surfaced in several investigations reviewed by Commission staff.

Similarly, as noted in the summary of the shaving incident, the investigator and the Director of Quality Assurance who reviewed the investigation failed to ensure follow-up of the alleged assault (blow to the eye) reported by one of the residents involved. Further inquiry by CQC determined that an incident report regarding the eye injury had never been filled out and, consequently, no inquiry into the allegation was conducted.

The failure to interview all relevant parties and pursue questions raised during the investigation, shortcuts in taking statements and drawing conclusions in the absence of any evident basis for them surfaced in several investigations reviewed by Commission staff. For example:

- On Friday, October 5 at approximately 1:15 p.m., a resident reported to a therapy aide that another therapy aide had choked him a few minutes earlier. He named a second therapy aide as a witness, and given the circumstances of the incident, it must have been witnessed by several residents. The investigation summary leads with a description of the victim which reads, in part, "He is extremely emotional and gets very upset if he doesn't get his own way. Once frustrated he becomes verbally abusive and progresses to hitting others."

  The facility investigation revealed that there was no staff witness. One resident witness claimed the victim was choked, a second resident witness claimed there was no choke, but there was an altercation between the therapy aide and the resident. The psychologist concluded that the victim likely left the room and the subject (therapy aide) pursued him "putting his hands on his neck to stop the movement." The subject denied that there was any argument or altercation, that the resident tried to leave the room or that he touched the victim's neck or shoulder.

  Despite the testimony of two resident witnesses and the conclusion of the psychologist that an altercation of some kind occurred between the subject and the alleged victim, no follow-up interview of the subject was conducted questioning his proffering of what appears to be false and misleading information.

  The facility noted that the results of the investigation were inconclusive. As there were no marks on the victim's neck, the investigator theorized that the victim accused the therapy aide because the aide would not let him have his own way. While this conclusion may be true, there is insufficient evidence to support it. Further, despite the testimony of two resident witnesses and the conclusion of the psychologist that an altercation of some kind occurred between the subject and the alleged victim, no follow-up interview of the subject was conducted questioning his proffering of what appears to be false and misleading information.

- A male resident was discovered at 6:15 a.m. with a one inch laceration to his scrotum requiring three sutures. Staff statements taken during this investigation repeatedly note that the resident did not participate in the 5:00 a.m. fire drill on the day in question. Yet, the investigator did not pursue this issue. No one questioned where he was or what he was doing and there was no clinical response to this potentially dangerous behavior.

  The investigation summary concluded that the origin of the injury remained unknown. The Director of Quality Assurance concluded that the injury must have been accidental, probably sustained on the bed rails.

- On June 30, 1990, resident Patrick Harris was found by staff assisting him to bathe to have a large ecchymotic and swollen area on his penis. He was sent to the Emergency Room of the local hospital for further examination and tests. Urine tests revealed no signs of internal bleeding and Mr. Harris was discharged with instructions to return him to Emergency Room if he showed signs of decreased output or bloody urine. Eight direct care staff mem-

bers were asked to provide written statements; three claimed in a very short signed statement to know nothing about the injury. There is no indication that any of these three staff were interviewed about Mr. Harris' behavior that day despite the revelation in the statement of the therapy aide who discovered the injury, that Patrick had refused to go to the dining room for dinner and was in the same chair when he (the therapy aide) returned from dinner with the residents under his supervision.

No one addressed the fact that he was left alone on the unit and no one was held accountable.

The Director of Quality Assurance concluded that because the resident had a history of masturbation, his injury was "self-inflicted, probably as a result of vigorous masturbation." The Treatment Team met following this incident and recommended that Patrick be closely supervised especially during leisure hours and that he receive sexuality counseling. No one addressed the fact that he was left alone on the unit and no one was held accountable.

Incident Review Committee Proceedings

THE INCIDENT REVIEW COMMITTEE PROCESS AT BERNARD FINESON DEVELOPMENTAL CENTER HAD SEVERAL SERIOUS FLAWS DESPITE THE FACT THAT IRC MEMBERS PAY CLOSE ATTENTION TO SEVERAL ASPECTS OF THEIR ROLE. THERE WAS NO ACCOUNTABLE PROCESS FOR ENSURING THAT ALL INCIDENTS ARE REVIEWED; THE MINUTES RECORDED DELIBERATIONS ONLY IN SELECTED CASES; AND, IN SEVERAL INSTANCES, THE MINUTES RAISED QUESTIONS ABOUT THE ADEQUACY AND THOROUGHNESS OF THE REVIEW.

Every facility is required to have a standing committee to review untoward incidents to ensure that they have been thoroughly investigated and that appropriate preventive and corrective measures, including disciplinary actions, have been recommended.

The IRC at Bernard Fineson Developmental Center meets monthly and reviews incidents from all three developmental center sites and the community. As noted earlier, every facility is required to have a standing committee to review untoward incidents to ensure that they have been thoroughly investigated and that appropriate preventive and corrective measures, including disciplinary actions, have been recommended. A mix of people from various disciplines and with different job assignments and representatives from outside the institution help to broaden the perspectives available to evaluate incidents and corrective measures. The Bernard Fineson Committee is chaired by the Director of Quality Assurance and, in addition to executive staff of the facility, includes a therapy aide, a representative of the Board of Visitors, a Mental Hygiene Legal Services attorney, a member of the Willowbrook Class Consumer Advisory Board and a member of the Parent Association.

A review of the minutes of seven meetings from July 1990 through January 1991 revealed that the Committee has successfully devised a method to ensure that incomplete old business is reviewed until the Committee reaches closure. That is to say, old issues and requests for additional information are tracked and referenced month-to-month until the issue is resolved.

For example, in reviewing the incident involving Patrick Harris in July 1990, the Committee questioned whether, in view of the determination that the injury was self-inflicted by masturbation, the resident was receiving sexual counseling. The following month, the IRC minutes noted that the Committee had received the revisions made to Mr. Harris' treatment plan which stated that he would be given counseling.

The IRC also made two generalized requests for more comprehensive information — one to physicians requesting that STAT medications given at the time of an incident be identified and the dosage specified, and one to direct care staff asking that they specify which less restrictive measures were used before resorting to take-downs.

While this evidence suggests that the IRC members pay close attention to certain aspects of incident review, an examination of the IRC minutes reveals other problems in its deliberations. Such a review is hindered, however, because:

- The Committee records minutes of its deliberations for only selected cases. For example, the October, 1990 minutes indicate that the Committee reviewed three serious incidents and 46 reportable incidents from the Corona Unit. The minutes provide a short narrative description of seven incidents and the related comments or questions of the Committee.
- Because the 42 reportable incidents not commented upon are not identified in any way, even by incident report number, it is impossible to determine through the minutes whether all incident reports reached the Committee and were reviewed.
- Similarly, a review of the minutes does not clarify how the additional four incidents from the 46 reportable ones were selected for recorded discussion as several serious incidents (although not classified as such) to be discussed below were not referenced.
- A review of those cases which are commented upon raised questions regarding the thoroughness of the Committee's review of the adequacy of the investigations and resulting recommendations.

Deficiencies in the minutes are consequential because the minutes are a primary vehicle for keeping program managers and the governing body advised about the status of incident reporting.

The deficiencies in the minutes are consequential because the minutes are a primary vehicle for keeping program managers and the governing body advised about the status of incident reporting. They also provide a finger on the pulse of the facility, providing feedback on such issues as the effectiveness of training around problem issues, potentially serious safety issues, residents having particular difficulties and staffing problems, etc.

The two examples cited below are incidents reported within a five month period which were either serious or which raise questions regarding the adequacy of supervision or attention to other safety measures. These cases were not reviewed by the IRC.

- In the early morning, a severely retarded resident was found to have blood on his underwear. Medical examination determined that the young man had recently sustained a one inch moderately deep longitudinal laceration to his scrotum. The wound was closed with three sutures. The investigation was unable to determine how the injury was sustained and concluded that there was no evidence to suggest abuse.
- At approximately 11:00 p.m. a severely retarded male resident was observed leaving the bedroom of a neighboring resident who is

mildly mentally retarded. When questioned, he replied that his neighbor had just burned his (the visitor's) penis. A medical exam confirmed the presence of a small blistered area.

As noted, in addition to the absence of any information regarding the Committee's disposition on the vast majority of cases, a review of those cases which are commented upon also raised questions about how thoroughly the Committee reviewed the adequacy of the investigations and resulting recommendations.

For example:

- A review of IRC minutes of the Patrick Harris incident reveal that, although the IRC correctly questioned whether Mr. Harris was being counseled regarding sexual activity, the Committee did not question why Mr. Harris' supervision during dinner time had not been pursued.
- Similarly, in reviewing an incident between two male residents wherein one claimed to have been forcibly sodomized by the other in the lobby bathroom, the Committee, following the lead of the facility investigation, determined that the sodomy did take place, but that there was no coercion involved. The IRC did not question the capacity of the individuals to consent to sexual activity, and did not decry the absence of this essential information in the investigation. In fact, both residents had been determined *incapable* of consenting to sexual activity. The IRC did question why an incident report had not been filed for the second man involved and, according to the minutes of a later meeting, accepted the feeble rationale that "he did not participate in any event."

In addition to the absence of any information regarding the Committee's disposition on the vast majority of cases, a review of those cases which are commented upon also raised questions about how thoroughly the Committee reviewed the adequacy of the investigations and resulting recommendations.

- The IRC minutes of the incident involving Debra Miller and Michael Evans concluded with the facility investigation that there was no sexual abuse because there was no physical evidence of sexual intercourse. There is no indication that the Committee questioned the possibility of other activity having occurred, and it failed again to ascertain and consider the implication of the clinical team's prior determination that Debra did not have the capacity to consent to sexual activity and that Michael had the capacity to consent "with counseling."

  Evidencing a failure to critically review the details of the investigation similar to that evident in the Committee's review of the incident involving Patrick Harris, the Committee never questioned why the "stack of female underwear" (per statement of the safety officer) found in the stairwell was not investigated further.
- In an October 1990 incident in which a moderately retarded male resident alleged he raped a severely retarded female resident, while the investigation clearly established that the woman had asked the man to "rape" her and both used the term synonymously with sexual intercourse, neither the investigator nor the IRC questioned the capacity of the individuals to consent, and did not question the young

man's statement that he had had sexual intercourse with her on several occasions and that she "asks other male clients to rape her and have sex with her almost everyday." The facility had, in fact, found her incapable of consenting. Yet, there was no treatment response to the young woman's alleged frequent requests for sex from a number of men. As seen in earlier cases, neither the investigator nor the IRC questioned the adequacy of supervision, although the male claimed that he and his partner and a second female (who witnessed the incident) slipped away while the other residents and staff were watching a video.

The examples cited indicate a need to retrain those staff members assigned to investigate incidents and those who review the investigations.

The examples cited above indicate a need to retrain those staff members assigned to investigate incidents and those who review the investigations. These include the Special Investigators who investigate all allegations of abuse and any other serious incidents as requested, the Team Leaders and Unit Administrators who investigate all other incidents and the members of the IRC. This recommendation is further supported by the facility's acknowledgment that presently there are no guidelines governing the procedures and parameters for investigations.

Corrective Action Implementation Questionable

INTERVIEWS WITH SOME MEMBERS OF THE IRC AND A REVIEW OF THE IRC MINUTES FROM JULY 1990 THROUGH JANUARY 1991 REVEALED THAT THERE WAS NO MECHANISM IN PLACE TO ENSURE THAT CORRECTIVE MEASURES ARE IMPLEMENTED AS RECOMMENDED OR THAT THE MEASURES RECOMMENDED ARE MONITORED TO ENSURE THEIR EFFECTIVENESS.

Staff reported that if a problem does not resurface, they assume it had been dealt with effectively. Commission staff were not able to review corrective action implementation on a broad basis. However, the absence of a tracking mechanism to ensure effective resolution to problems was apparent

Rather, staff reported that if a problem does not resurface, they assume it had been dealt with effectively. Commission staff were not able to review corrective action implementation on a broad basis. However, the absence of a tracking mechanism to ensure effective resolution to problems was apparent in the varying degrees to which corrective actions were implemented following the pubic hair shaving incident and the incident involving Debra Miller and Michael Evans.

The facility investigation had concluded that no staff member noticed that the six residents were missing from 6:30-7:30 p.m., in large measure because no specific staff member had been assigned to watch them. To correct this, the Treatment Team Leader instructed the mid-level supervisor to ensure that all residents were members of a small group and that each small group was assigned to a specific staff member. These small groups were to be engaged in recreation programs during the time after supper and before preparing for bed. To prevent residents from returning to their bedrooms unobserved, the mid-level supervisor was to ensure that client bedroom doors were kept locked (until bedtime) and opened only at the request of the resident.

Commission staff observed the after-dinner activities on the sixth floor on January 30. At that time, the mid-level supervisor could not explain which residents were in what group and who was supervising whom. A check of the bedrooms indicated that several were unlocked and unoccupied, and others were unlocked and the residents were resting, some with direct staff supervision, all with staff knowledge.

Turning aside from a discussion of the propriety of the recommendation to lock all bedroom doors, it was clearly the intent of the recommendations to ensure that residents were precluded from engaging in clandestine behaviors that might prove injurious by ensuring supervised recreational activities during which specific staff were accountable for specific groups of residents. Both the Commission observers and the Bernard Fineson Developmental Center staff accompanying them agreed that this was not occurring.

In contrast, following the review of the incident involving Debra Miller and Michael Evans, the facility recommended, among other things, that the stairwell door be locked and not accessible to residents, and that when moving to and from the dining room, all residents travel in groups with a specific staff member assigned to each group. During the Commission's observations, these recommendations were being followed. Staff accountability for a specific group of residents extended, in fact, beyond transporting people to and from the dining area several floors below, and included assistance and supervision throughout the meal.

Where Next?
— Additional Recommendations

The administration of Bernard Fineson DC has recognized some of the problems identified in this report and has undertaken corrective action. These initial steps are clearly necessary and must be followed by others.

The administration of Bernard Fineson DC has recognized some of the problems identified in this report and has undertaken corrective action. The Director has instructed staff to review ward logs to ensure that all incidents mentioned there are properly reported. This has been incorporated as part of each Team Leader's routine duties. The Director has also arranged for training on incident reporting and investigation from the Central Office of the OMRDD. Finally, the facility has determined that *all* incidents of a sexual nature will be reviewed by the IRC.

These initial steps are clearly necessary and must be followed by others. Specifically, the facility needs to:

- provide intensive training for special investigators and the chair of the IRC to ensure that incidents are appropriately classified and investigated;
- establish guidelines for the comprehensive review of various types of incidents which also clearly identify which incidents must be reviewed by Special Investigators;
- provide training to IRC members to enable them to assess the quality of investigations and the need for corrective action;
- develop a format for IRC minutes which will identify all of the incidents reviewed;
- develop a mechanism whereby recommended corrective actions are promulgated, implemented and monitored to ensure their effectiveness;
- develop in cooperation with the OMRDD Central Office an internal review system to periodically assess the effectiveness of the incident reporting, investigating and review system, and circulate these findings within the facility and to the OMRDD Central Office; and
- ensure effective protection from sexual exploitation to those persons determined not capable of consenting to sexual activity, in part, through staff training in consent issues and in the proper responses to the sexual expressions of residents.

In order to further ensure the safety of residents in the care of the OMRDD, the Commission recommends that the Office undertake a review of incident reporting and review procedures at its other facilities to ensure that serious incidents are properly classified, competently and thoroughly investigated and reviewed, and effective corrections actions are implemented. This review should also examine the facilities'

practices in reporting incidents to oversight and law enforcement bodies outside the facility.

The final CQC recommendation deals with the larger issue of how best to serve the residents of Bernard Fineson to offer them an opportunity for growth and learning. All persons involved in the closure of developmental centers and the opening of community programs recognize that the individuals presently remaining at the centers generally present a challenge to clinicians, either because they are multiply disabled (this includes persons with autism, severe sensory and motor deficits, or a psychiatric diagnosis and the medically frail) or because of their aggressive or self-injurious behaviors.

The remedy is easily identified and described. It is not easily accomplished. The residents need to live in much smaller groups with more space. Severely handicapped persons who are particularly vulnerable should not live with persons with seriously aggressive physical and sexual behaviors.

At Bernard Fineson D.C. these challenges are compounded by the mix of residents on the units, which leaves persons with modest or moderate deficits living with persons with severe intellectual impairments, and sexually active residents living with persons whose level of developmental maturity would preclude most sexual activity with another person. At the Center the depressing institutional living environment with limited common space and few meaningful options for recreation and the use of leisure time adds to the problem.

All of these impediments are driven by the woefully inadequate number of community placements available in Queens for residents of the Developmental Center. According to Bernard Fineson's Executive Director, voluntary agencies have multiple candidates for each bed that becomes available and generally do not choose people whose aggressive behavior has been shaped by years of institutional living. Since the State operates just five residences in Queens, only a few vacancies become available each year. Thus, persons with IQ scores in the 50 to 80 range who, had they lived in other areas of the state, would likely have been moved to the community years ago, are confined to the Center. Sadly, these residents are not presently learning the adaptive skills they will need in the community, as both residents and staff are victims of an environment where aggression is common. While the injuries inflicted are minor as evidenced by the treatment records and logs, the pervasiveness is unmistakable.

The remedy is easily identified and described. It is not easily accomplished. The residents need to live in much smaller groups with more space. Severely handicapped persons who are particularly vulnerable should not live with persons with seriously aggressive physical and sexual behaviors. And, persons with these behaviors should not be congregated together in groups of 10-12 (the size of many community residences) while they receive the specialized training and supervision their behaviors warrant.

Present plans call for the placement in the community of all Willowbrook Class persons presently living in Bernard Fineson by 1992. Seventy-two community beds are planned for development in 1990-1991 and 200+ beds each of the next two fiscal years. While the entire center is slated for closure by the year 2000, the OMRDD notes that closure of the Corona Unit is possible by FY 1992-1993.

The Commission urges the OMRDD to give very careful scrutiny to the closure plans to ensure that the transfer of incompatible groups of residents from the D.C. to large ICFs does not merely change the setting of an unacceptable standard of care.

The Broader Issues

Throughout the course of this investigation, the Commission sought to understand the reasons why incidents of forcible sexual assaults, attempted rape and sodomy were not reported and investigated as required by law and regulations. A consistent explanation proffered by staff and administrators was confusion about and a lack of understanding of the concept of capacity to consent and its effect upon the sexual activity among residents.

Providers of service to adults who are mentally retarded undertake difficult and complex societal obligations. On the one hand, they are expected to provide care, habilitation and support services to enable these individuals to develop all of their abilities and potential to function as normally as possible despite the limitations inherent in their disabilities. On the other hand, they have a clear duty to protect persons in their care and custody from harm.

One of the areas where these dual obligations raise some of the most difficult and troubling conflicts is the sexual aspect of the life of persons with mental retardation.

There is little guidance available to programs as they move from the times when sexual activity among mentally retarded persons in institutions, although commonly practiced, was a taboo subject, never discussed, much less addressed as a clinical and legal issue.

There is little guidance available to programs as they move from the times when sexual activity among mentally retarded persons in institutions, although commonly practiced, was a taboo subject, never discussed, much less addressed as a clinical and legal issue. The conspiracy of silence relegated sex between residents of institutions to furtive encounters which carried no likelihood of deepening the relationship between the partners. Fortunately, mentally retarded persons, their families, friends and advocates have taught us that these attitudes stole from competent developmentally disabled adults a fundamental human right.

"Giving back" the right to sexual expression while protecting vulnerable people offers a multitude of challenges, particularly at a time when indiscriminate sex can cost one's life. The concerns of clinicians that residents receive adequate training and counseling to assist them to put sex in the context of the variety of kinds of relationships available to them, the concerns of medical staff that residents be taught about safe sex and sexually transmitted diseases, the concerns of parents and advocates that residents learn how to protect themselves from unwanted advances, and the concern of direct care staff that privacy issues be handled appropriately are just the tip of the iceberg. Indeed, the task would be somewhat easier if these concerns were in actuality so neatly compartmentalized. The truth of the matter is that everyone who has thought about this issue worries about all of these and more.

Being mentally retarded does not bar an individual from having a sexual life. Like other adults, competent mentally retarded people are

free to develop intimate relationships, to marry and to procreate. In such circumstances, providers of services, who often stand *in loco parentis* to their clients, are expected to provide the education and training to enable their clients: to understand their sexuality; to know and assess the nature, risks and consequences of sexual activity; to take measures to protect themselves against disease or unwanted pregnancies; and to make informed decisions about sexual activity.

At the same time, however, when a provider is aware that a person with mental retardation does not have the capacity to make informed decisions about sexual activity, and that this incapacity cannot be overcome by education and training, the legal obligation is to protect the individual from harm.

At the same time, however, when a provider is aware that a person with mental retardation does not have the capacity to make informed decisions about sexual activity, and that this incapacity cannot be overcome by education and training, the legal obligation is to protect the individual from harm. This requires vigilance to ensure that the person is not sexually exploited by other residents or staff, particularly since the incapable individual may be in no position to assess the nature of the risk entailed or to protect himself or herself from such risks. As a practical matter, this may result in barring such incapable individuals from some forms of sexual activity with others.

To many staff and clinical professionals in this field, this result seems harsh and restrictive of the legal right of mentally retarded people to be treated equally to other adults because it precludes to many such individuals an important and powerful source of emotional and physical satisfaction. But the law leaves little choice.

Legislators, who have wrestled with the issue of determining when sexual conduct between adults is a crime, have consistently concluded that lack of consent by reason of mental disease or defect renders most sexual conduct criminal when the victim is "incapable of appraising the nature of his conduct." (NY Penal Law, §130.00, subd.(5)) The State's highest court, in an unanimous decision, has stated that "the law does not adopt the fiction that all persons are mentally or judgmentally equal." The court elaborated upon the elements of genuine consent to sexual conduct by saying that, to be competent to consent, an individual must have an understanding of more than the physiological nature of the sexual activity and its consequences. There must be an ability to *understand and appreciate* how such conduct will be "regarded in the framework of the societal environment and taboos to which a person will be exposed. . . In that sense, the moral quality of the act is not to be ignored." (*People v. Easley*, 42 NY2d 50, 56 (1977), emphasis added).[3]

[3] The facts of that case are instructive in understanding the law. A young woman living with her grandmother engaged in an act of intercourse with a family friend who had been living in the same household. She tested in the moderately mentally retarded range with an IQ of 45-54. A psychologist testified that she could respond to sexual stimulation, participate in the act of intercourse and comprehend that it could result in "having a baby" but was incapable "of thinking beyond the act in terms of what the consequences could be." Her grandmother testified how her efforts to broach the subject of sex had been met with "almost total incomprehension." The court found her incapable of consenting and affirmed a conviction of rape.

The Court of Appeals in *Easley* recognized that the standards for determining competence are not "precise and inelastic." There is no clear, bright line to distinguish those with sufficient capacity, who should be accorded reasonable rights of privacy and sexual expression if they desire, from those whose lack of capacity invokes the custodian's obligation to protect them from sexual harm, abuse and the risk of exploitation. These are determinations for which the law relies, in the first instance, upon the sound exercise of judgment by competent professionals.

These legal precepts are incorporated into State regulations issued by OMRDD which govern the operation of its developmental centers and the other facilities and programs it certifies (14 NYCRR Part 624). These regulations define as "sexual abuse" all sexual activity between clients and others or among clients unless the involved clients are "consenting adults." (Part 624.2(b)(2))

The regulations require that such incidents be reported, investigated and reviewed to "ensure that immediate steps are taken to protect other clients from being exposed to the same or similar risk" (Part 624.2(b))

There is no clear, bright line to distinguish those with sufficient capacity, who should be accorded reasonable rights of privacy and sexual expression if they desire, from those whose lack of capacity invokes the custodian's obligation to protect them from sexual harm, abuse and the risk of exploitation.

However, the Commission has become increasingly aware that some staff, clinicians and administrators disagree with the foregoing understanding of the law which may preclude the participation of many incapable mentally retarded people in the pleasure of sexual relationships. They argue that sexual activity is embraced by the privacy rights of their clients. They appear to believe that as long as residential facilities ensure safe sex practices (birth control, condoms, and testing and treatment for sexually transmitted diseases), the sexual lives of all people who are mentally retarded should remain free from intrusion, and should not be the subject of reports and investigations, absent evidence of physical coercion.

This investigation into the operations of BFDC illustrates the dangers to which persons who are mentally retarded can be exposed when those charged with their care and protection disagree with and choose to disregard a well-established body of laws and existing regulations which require the reporting, investigation and review of conduct defined as "sexual abuse." In the absence of a satisfactory alternative to settled law and existing regulations, the protection of residents rests on the slender reed of the varying judgments of individual administrators and staff, judgments which have not consistently proved reliable in ensuring the protection of vulnerable people. The facility must deal with these issues and state clearly its philosophy and how it will be implemented. This statement must include an unqualified declaration that vulnerable people will be protected.

The Commission recognizes that it is often the case that the evolution of the law follows changes in societal norms and practices. Over the past two decades, our society has been undergoing profound changes in the manner in which it deals with people who are disabled. Courts have been recognizing that many people who are mentally retarded have been arbitrarily and unnecessarily deprived of liberty, often based upon the

lack of appreciation of their abilities to live more independent and normal lives. Normalization has become an explicit or implicit goal of virtually every state mental retardation system.

Numerous laws have been enacted at the state and federal level recognizing the rights of people who are mentally retarded to the fruits of citizenship. The most recent such expression of public policy is the Americans with Disabilities Act, which declares a broad policy of non-discrimination on the basis of disability. It requires "reasonable accommodations" to adapt practices to permit the inclusion of people with disabilities in the life of the community.

These significant changes in societal understanding of the needs and abilities that people with disabilities have in common with those not disabled may very well warrant a reconsideration of the manner in which the law deals with the rights of people who are mentally retarded to sexual expression. The tests for informed consent that legislators and courts have created may require modification in light of our evolving understanding of the importance of sexuality in normal adult human relationships for all people, including those with severe mental disabilities. High thresholds of cognitive understanding of functions that are essentially physiological, which have the effect of depriving subgroups of adults of any possibility of sexual relationships, may be replaceable by other evidence of effective consent to sexual relationships.

The tests for informed consent that legislators and courts have created may require modification in light of our evolving understanding of the importance of sexuality in normal adult human relationships for all people, including those with severe mental disabilities.

But such a reconsideration by law makers and courts is unlikely to occur if clinical professionals fail to make the effort to develop and articulate alternative methods of examining and determining capacity to consent. A thoughtful articulation of an alternative view, drawn from clinical and practical experience, and supported by significant professional opinion, would command the attention of the field, as well as of the legal system. It would help fill the void left by the private dismissal and disregard of existing law and regulations. At the same time, it would protect vulnerable people from the vagaries of private attitudes and policies on sexuality.

The Commission is aware, for example, that the Supreme Court of New Jersey, in recently deciding a case very similar to *People v. Easley*, established a different test for determining capacity to consent to sexual relations by a mentally retarded person. In *State of New Jersey v. Olivio* (123 N.J. 550, decided May 1, 1991), that Court ruled that a person is "mentally defective" under the New Jersey statute "if, at the time of the sexual activity, the mental defect rendered him or her unable to comprehend the distinctively sexual nature of the conduct or incapable of understanding or exercising the right to refuse to engage in such conduct with another."

The Court elaborated:

> The statutory concept of "mentally defective" implicates both the intellectual or cognitive capacity and the volitional or consensual capacity of the individual with respect to personal sexual activity. The consensual capacity involves knowing that one's body is private and is not subject to the physical invasions of another, and

that one has the right and ability to refuse to engage in sexual activity. The cognitive capacity, which is also implicit in the notion of consensual capacity, involves the knowledge that the conduct is distinctively sexual. In the context of this criminal statute, that knowledge extends only to the physical or physiological aspects of sex; it does not extend to an awareness that sexual acts have probable serious consequences, such as pregnancy and birth, disease, infirmities, adverse psychological or emotional disorders, or possible adverse moral or social effects.

It is clear that the New Jersey Supreme Court's formulation of a test for capacity would result in a finding that many more mentally retarded people have the capacity to consent than under the New York Court of Appeals' ruling in *People v. Easley*.

But, until such an alternative view is articulated and gains acceptance by lawmakers and the courts, the Commission sees no viable option, consistent with the duty to protect from harm, to a scrupulous adherence to the existing New York State law and implementing regulations.

The Commission therefore urges the OMRDD to convene a professional forum to fully consider all aspects of this sensitive subject and either restate and elaborate upon the expectations embodied in current law and regulations or develop such further policy guidance as it may deem appropriate.

Summary of Recommendations

In order to facilitate a review of the Commission's recommendations, they are gathered below from throughout the report.

The Commission recommends that Bernard Fineson Developmental Center implement the following corrective actions:

- provide intensive training for special investigators and the chair of the IRC to ensure that incidents are appropriately classified and investigated;
- establish guidelines for the comprehensive review of various types of incidents which also clearly identify which incidents must be reviewed by Special Investigators;
- provide training to IRC members to enable them to assess the quality of investigations and the need for corrective action;
- develop a format for IRC minutes which will identify all of the incidents reviewed;
- develop a mechanism whereby recommended corrective actions are promulgated, implemented and monitored to ensure their effectiveness;
- develop in cooperation with the OMRDD Central Office an internal review system to periodically assess the effectiveness of the incident reporting, investigating and review system and circulate these findings within the facility and to the OMRDD Central Office; and
- ensure effective protection from sexual exploitation to those persons determined not capable of consenting to sexual activity, in part, through staff training in consent issues and in the proper responses to the sexual expressions of residents.

The Commission also recommends that the Office of Mental Retardation and Developmental Disabilities take the following measures:

- undertake a review of incident reporting and review procedures at its other facilities to ensure that serious incidents are properly classified, competently and thoroughly investigated and reviewed and effective corrections actions are implemented. This review should also examine the facilities' practices in reporting incidents to oversight and law enforcement bodies outside the facility.
- give very careful scrutiny to the closure plans to ensure that the transfer of incompatible groups of residents from the D.C. to large ICFs does not merely change the setting of an unacceptable standard of care.

- convene a professional forum to fully consider all aspects of this sensitive subject and either restate and elaborate upon the expectations embodied in current law and regulations, or develop such further policy guidance as it may deem appropriate.

Corrective Actions

The Office has prepared draft guidelines for addressing the sexual activities of developmentally disabled persons which it will be sharing with providers seeking their critical comment. In addition, the Office has begun an internal study of the functioning of the incident reporting, investigation and review process at all of the developmental centers in New York City.

In response to the findings and recommendations in this report, the OMRDD has undertaken corrective actions to ensure the safety and safeguard the rights of residents of OMRDD operated and certified programs. Specifically, the Office has prepared draft guidelines for addressing the sexual activities of developmentally disabled persons which it will be sharing with providers seeking their critical comment. In addition, the Office has begun an internal study of the functioning of the incident reporting, investigation and review process at all of the developmental centers in New York City. At the time of the publication of this report, the on-site portion of the review of the effectiveness of the corrective actions taken by Bernard Fineson Developmental Center had been completed and the findings of the report were expected shortly.

The administration of Bernard Fineson D.C. also marshalled its resources to initiate broad-based changes at the facility. It reports having taken the following actions:

- Incident reporting policies and procedures were rewritten and administrators were instructed in their implementations;
- The BFDC Human Sexuality policy was revised and all ward staff were retrained;
- Special investigators were designated and trained and supervision/ critical review of their work ensured;
- Administrators and IRC members also received special investigation training;
- A procedure has been established to ensure that all incident reports are properly classified;
- A new format was developed for the IRC minutes;
- A follow-up sheet was developed to alert Unit Administrators to IRC recommendations they are responsible for implementing; and
- Residents of the sixth and seventh floor were reassigned to establish groupings of persons with similar abilities and needs.

At the request of the Director of Bernard Fineson D.C., the New York City Regional Office of the OMRDD has designated a monitor to oversee the effective implementation of the facility's strategies for ensuring compliance with the OMRDD incident reporting regulations. The regional office representative will monitor the implementation and effectiveness of the actions outlined above, attend IRC meetings for six months and quarterly thereafter, and verify the effective follow-up of IRC recommendations quarterly. The monitor will submit a written quarterly report to the Director, Associate Commissioner and Commissioner.

The Commission, with the OMRDD, is hopeful that these measures will significantly enhance the quality of life afforded residents of all developmental centers through a heightened appreciation of the protections afforded to vulnerable persons by a competent and aggressive review of untoward incidents.

OMRDD has promulgated draft guidelines regarding consent to sexual activity to assist facilities and their staff in understanding and carrying out their twin obligations to promote normal living and to protect vulnerable people from harm. OMRDD has indicated an intention to seek additional input from consumers, families, providers, and advocates on the content of these guidelines, prior to finalizing them.

The Commission fully supports the OMRDD's efforts to address the long-standing void in policy guidance to facilities on this difficult and complex subject.

The Commission on Quality of Care for the Mentally Disabled is an independent agency responsible for oversight in New York State's mental hygiene system. The Commission also investigates complaints and responds to requests concerning patient/resident care and treatment which cannot be resolved with mental hygiene facilities.

The Commission's statewide toll-free number is for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.

Toll-free Number: 1-800-624-4143

TDD Number for Hearing Impaired Individuals: 518-473-7871